

7. Appendix

Sample Materials for Teaching Medical Ethics with Parent Collaborators

Questions for discussion after viewing *Dreams and Dilemmas: Parents and the Practice of Neonatal Care*

What ethical issues do you see reflected in this film?

- Who should make decisions about treatment for newborns?
- What is the balance between considerations of quality of life and preserving life?
- How does the amount of information shared and the way it is shared affect parents' ability to make informed decisions for their children?

What ethical issues do you see reflected in this film?

- How do you as a team make medical decisions when different people (parents, physicians, nurses, social workers, chaplains) see the situation differently?
- How do you make medical decisions in the face of significant uncertainty?

How do communication issues affect ethical decision-making?

- Physicians have access to information that parents can get only from physicians—e.g., test results, technical knowledge.
- Physicians gain access to data about an infant before parents, and set the timing for sharing the data
- Prior life experience shapes the perspectives of all parties

How do communication issues affect ethical decision-making?

- Parents may be at different points in their understanding, values, or perspectives
- Healthcare professionals may have differing views about how much information to share with parents, how to share it, or how directive to be
- Choice of vocabulary affects the way parents understand

What questions would you ask the parents in this film to help you build an understanding of their perspectives?

- What are your fears?
- What are your hopes?
- What do you want for your children?
- What do you want to know to make a decision about a DNR order?
- What do you want to know to make a decision about continuing support?

What questions could you ask these parents to help you build an understanding of their perspectives?

- How could I as a physician help you?
- What does quality of life mean to you?

A summary of *Dreams and Dilemmas* for parents to read before viewing the film with medical students and discussing their own children's stories in small groups.

*Dreams and Dilemmas*¹

**A film by R. Kahn with the Ethics Institute at Dartmouth College
Summarized by Lyetta Griffin, Parent-advisor**

This is the story of Travis and Thomas, twin baby boys born premature.

Tuesday—Travis has a very bad injury to the brain when his brain stopped growing and started to atrophy. The doctor states it is extensive and an awful situation. Do you want to limit support? Travis' prognosis is grim with him being below the 10% growth percentile. He will have a long-standing brain injury. The doctor will limit support if the parents agree. The priest feels the doctor should direct the parents. The doctor informs the parents they will have a severely handicapped son. Do they have any personal family experience with this type situation? Travis has very severe damage on both sides of the brain. The father feels that Travis was meant to be here. There is good potential for long term care with Travis not being self-sufficient. His intellectual ability is virtually non-existent or very, very poor. How fair is this for a baby boy? Would a parent want this life for their child? There is no change in treatment.

Wednesday brings a new set of problems. Travis will not walk or feed himself. It will take him a long time to learn to suck and swallow and big doubts as to whether he can talk or communicate. The father is crying—he doesn't want this for his son. There are a lot of problems ahead in regard to treatment. The doctor doesn't recommend CPR for Travis. Both parents are crying. His care will not change but maybe God will take a hand. The question posed to the parents—Do you want a Do Not Resuscitate order???

Thursday comes with more issues. The quality of life for Travis wouldn't be very good. He could say "hi" to mom and dad and sit in a wheelchair. He could also be in bed for 20 years with no speaking. That would involve a feeding tube. The mother has a strong faith in God. Dad could not live with himself if he made the wrong decision.

Friday the primary care team meets to discuss Travis. Travis may fight to survive and it is equally hard for the parents to give up hope. What will life be like for the family later on for school and other issues? This could be very overwhelming for his parents and affect his family for a long time. Would it be better for Travis not to survive?? The parents decide not to stop current treatment but not to resuscitate him if his heart stops.

Saturday Travis was treated for an infection with antibiotics; nothing else was done. Travis died in his mother's arms.

Thomas, the other twin, also had problems. In April, he was in a state of metabolic acidosis along with some wheezing and a thick heart. The marriage became strained, what with different coping skills for the parents. His heart had become a major issue because of the valves. Echocardiograms were done frequently to assess the valves. His heart surgery went just fine. Nursing care and respiratory therapy were set up in the home. After 5 ½ months, Thomas went home.

¹ *Dreams and Dilemmas: Parents and the Practice of Neonatal Care*, a film by Richard Kahn with the Ethics Institute at Dartmouth College. Running time 58:02. Available from Fanlight Productions. 1998.

7. Appendix

Instructions for parents who participate in an ethics course

GUIDELINES FOR PARENT PARTICIPANTS

You are invited to lunch in a small room on the left side of the cafeteria in Building B at USUHS from 11:30 a.m. -12:45 p.m. Professor Howe plans to join us there. We will have a sandwich buffet, so if you can't get there right at 11:30, please join us when you can. We will meet outside the door to the cafeteria in Building B, on the ground floor at the entrance to the elevator from the parking garage, a little before 11:30. If you arrive after 11:30, go to room 2053 in Building A, wait for a parent to come back to meet you, or call Dr. Hanson's cell phone at xxx-xxx-xxxx.

From 1:00 p.m. -2:30 p.m., the ethics class will meet in Lecture Room D between Buildings C and D at USUHS (by the coffee bar). Professor Howe will introduce the ethics class, we will view part of a film about premature twins (*Dreams and Dilemmas*), and the large group will talk about the film. This film tells the true story of premature twins from the time of their caesarean delivery through the death of one twin, a very complicated hospital stay, and the time six months later when the second twin goes home to face an uncertain future with some significant disabilities. While this film shows some very sensitive professionals and some loving and dedicated parents, it is very emotional, especially for parents who have experienced a similar situation. You may want to bring some tissues. There is a written summary of the film in this packet.

After the film we will move to the cafeteria, where we will sit in groups of 6-8 for discussion. Each group will have one parent and six or seven students. Most groups will also have a faculty facilitator. You may want to bring a picture of your child to share when you introduce yourself to the group. In the small group, please be prepared to tell the story of your child and the critical medical decisions you have had to make. Also be ready to answer questions from the students and the following list of questions:

1. When and how did you first find out that your child had special needs? OR When and how did you receive your child's diagnosis?
2. What difficult medical decisions have you faced with your child?
3. What were the ethical issues involved in your child's situation? (e.g., whether the cost of the care was justified, whether your child's projected quality of life warranted the level of

medical intervention needed to keep him or her alive, whether the pain and suffering of your child was extreme, whether more could or should be done to save your child's life)

4. What role did medical information, doctors' opinions and your own values play in your decision-making?
5. What has been the outcome of these decisions for you and your child?
6. Should projections about long-term cost of care and quality of life play a role in these decisions? If so, how?
7. Have you seen any ways in which your decision-making about ethical issues has changed as a result of your experiences with your child?

After discussing your child's story with this group for 25 minutes, you will move to a second table and share your story with a new group of students. After 25 minutes with this group, you will move to a third table to discuss cases with another group of students. This group may want to discuss the film *Dreams and Dilemmas* and then move to the paper cases in the student packet. You may want to share your thoughts about the film and these cases during the discussion.

To prepare for this class:

- Read the guidelines for parent participants and summary of the film,
- Find a picture of your child to bring to the discussion, and
- Call Kathy (xxx-_____) or Jan (xxx-_____ work, xxx-_____ home) if you have questions.

Letters for parents who participate in an ethics course

Dear Parents,

We are delighted that you are willing to share your stories with our medical students on Tuesday, 23 August 2005.

Enclosed you will find some materials that may help you prepare for the class session. These include:

- Guidelines for you as a parent participant
- A summary of the film we will see during the lecture

We will do our best to reserve parking spaces for those who need them and who notify us in advance. We hope to have up to 35 participants, so please carpool with other participants if possible. ALL participants must have U.S. Government IDs or NMC Visitor Passes to enter the base. Military decals or visitor passes on the windshield are required for the USUHS garage. Please call Kathy Vestermark at (xxx) _____ if you need a Visitor Pass, Special Parking Permit, an accessible parking spot if you have health or mobility difficulties, a space for an oversized vehicle, or other special needs. If you don't have a parking pass, please park in the garage or in overflow parking lots noted on the enclosed map.

Please bring pictures of your child with you to the class. Also, think about whether you would like to invite the students to do a home visit at a later time. If you have any questions prior to the class, please feel free to contact Kathy Vestermark or Dr. Jan Hanson. We would be happy to answer any questions or address any concerns you may have.

Jan Hanson xxx-_____ work, xxx-_____ home
Kathy Vestermark xxx-_____ home

Thank you for assisting us in this important session. We appreciate your time and effort!

Sincerely,

Jan Hanson

Kathy Vestermark

Dear Parents,

Thank you so much for sharing your family's story at the ethics course this year. The afternoon went so smoothly and the students were so engaged in the discussions that we were, once again, amazed and grateful. As we say every year, your experiences help the students gain a perspective they cannot gain any other way--a parent's view of medical care in the face of major decisions for the children you love so very much. By placing a human face on what otherwise might remain just a set of paper cases, you convey the importance of compassion, good communication and appreciation for parents and physicians making difficult decisions in challenging circumstances.

As we said in the lecture session, this approach to teaching ethics is rare among medical schools. We are proud that the Uniformed Services University provides this opportunity for medical students, and grateful that you make it possible.

Sincerely,

Edmund Howe, M.D., J.D.
Professor of Psychiatry

Janice L. Hanson, Ph.D.
Assistant Professor of Medicine, Family
Medicine and Pediatrics

Kathryn Vestermark
Patient and Family Coordinator

7. *Appendix*

Guidelines for faculty facilitators for discussions about ethics with parents

FACILITATORS' GUIDELINES, ETHICS COURSE SESSION I

Today's session is a bit different from most discussion sessions in the bioethics class, because a parent participant will be at each table. All of these parents have experience with critical medical decisions concerning their children. Here is an outline for this session:

1. Introduce yourself and ask the parent in your group to introduce himself or herself.
2. Give the parent in your group an opportunity to tell his or her story. This is the first case of the session—a live case rather than a paper case.
3. Offer the students an opportunity to ask the parent questions. If you need further questions to generate discussion, here is a list of questions the parents are prepared to answer:
 - When and how did you first find out that your child had special needs? OR When and how did you receive your child's diagnosis?
 - What difficult medical decisions have you faced with your child?
 - What were the ethical issues involved in your child's situation?
 - What role did medical information, doctors' opinions and your own values play in your decision-making?
 - What has been the outcome of these decisions for you and your child?
 - Should projections about long-term cost of care and quality of life play a role in these decisions? If so, how?
 - Have you seen any ways in which your decision-making about ethical issues has changed as a result of your experiences with your child?
4. After 25 minutes, the parents will move to a second table. Ask this parent to share their story as described above.
5. After 25 minutes, the parents will move to a third table to discuss as above.
6. Paper cases or the film are available if the group needs additional material for discussion, but it's fine if the whole time is spent discussing the parents' stories.

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| <ol style="list-style-type: none">1. Parent tells story for 25 minutes.2. A second parent tells story for 25 minutes3. A third parent tells story for 25 minutes |
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